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ABSTRACT

Counseling parents of institutionalized adolescents and adults should address basic problems of parental overestimation of the child's impairment, anxiety regarding future community placement, and apprehension about the alternatives to community placement. Characteristic parental responses to their son's or daughter's placement in less restrictive settings include guilt and resistance, with the greatest rejection often expressed at the idea of foster care. (CL)

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"LIFE INSURANCE" FOR PARENTS OF RETARDED CHILDREN, ADOLESCENTS AND ADULTS: SHORT- AND LONG-TERM PARENT COUNSELING TECHNIQUES

Paper Presented at the 54th Annual International Council for Exceptional Children Conference, Chicago, April 1976

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"LIFE INSURANCE" FOR PARENTS OF RETARDED CHILDREN, ADOLESCENTS AND ADULTS: SHORT- AND LONG-TERM PARENT COUNSELING TECHNIQUES

Today fewer children are immediately institutionalized at birth. The continuing thrust of "normalization of care" and of "deinstitutionalization" may account for this change. Another, perhaps more important factor, accounts for it as well: The growing network of community-based services makes it possible for parents of children with developmental disabilities to receive services within their community and avoid institutionalization of their child.

In the past children with developmental disabilities were often institutionalized immediately after birth. The decision was frequently made by the physician and the father, both males, offering the mother a fait accompli. The increased awareness of women as to their right to be part of the decision-making process may well be contributing to the decrease of institutionalization of the developmentally disabled at birth.

By the time a child is institutionalized, the parents have been confronted with their own feelings of denial, isolation and anger. They may bargain, be depressed and finally accept their fate. All of these are frequently identified with the "dying patient." For this reason, counseling with parents of institutionalized offspring should not deal with their denial, isolation and anger, with their need to bargain, and their depression; it should deal with their acceptance of their child.

It has been my experience that counseling parents of children who have been institutionalized must deal with one or some combination of the following:

1. The need of the parent to see their child as more impaired than he or she is.
2. The anxiety of the parent with respect to decisions regarding future community placement.
3. The trepidation of the parents with regard to the choice of the alternatives to community placement.

It has been my experience with the parents of children and adolescents who have been institutionalized for many years that to deal with their own feelings of having institutionalized their child, they insist on seeing their child as "unable to learn." Even the popular media say there is a need to move from custodial care, to the use of a developmental approach. Nonetheless, many parents remain comfortable only with the notion of custodial care. Frequently, parents will point to that one thing in which their child has not shown progress. They contend: their child is not ready to make progress in this or that area. Their child has never shown a significant degree of success because of their physical impairment. For example, I have often seen staff proud and excited by the gains a child has made in eating and dressing, only to have the parent confront the staff and tell them: "But he can't talk" or "But he

can't walk." No matter how significant the success is in some areas, the parents insist their child "can't learn." They have provided themselves with the rationalization for their decision to institutionalize their child.

In counseling or psychotherapy, the guilt at institutionalizing their child must be made ego-alien (to reject or deny a given feeling). As long as parents continue to feel the guilt of having institutionalized their child, they will continue to have an overwhelming desire to see that child as more "defective" than he or she is.

The second area which should be addressed in counseling or psychotherapy is the feeling that they must continue for a lifetime to "pay their dues." It is not uncommon in the Metropolitan New York area for parents to travel by public transportation as much as six hours round trip to the developmental center to visit their child. These "pilgrimages" often become ritualized in that they occur on specific days and nothing else is permitted to interfere with these visits. Perhaps the parents feel, if they inconvenience themselves sufficiently by traveling long distances under uncomfortable circumstances, they are paying "their dues" for having had a retarded child. It is not at all surprising to learn that parents will often reject the offer of transportation to and from the center, in favor of the grueling six-hour trip. Again, from a counseling and psychotherapeutic perspective, it is necessary to intervene with the families of these children and adolescents to help them to see that this "need to suffer" is self-imposed and must be given up.

Closely tied to the need to see their child as more impaired or "more retarded" is the increased anger expressed by parents with respect to transferring their child to a less restrictive and more appropriate living arrangement within the community. The most frequent response from parents is that "my child is an institutional child" and can never make it on the "outside." Or: "He is too retarded; he will die."

Those who chose institutionalization are now pressured to participate in making new decisions for their offspring. It happens frequently that as soon as the parents hear that the recommendation has been made for an alternative placement in the community, such as family care or small group living. they are overwhelmed at the notion Not infrequently, they threaten to bring suit against the center.

In counseling and therapy, parents need to work toward developing the courage it takes to see their child function in a setting that is less restrictive. To see their child or adolescent function in a family care situation, in a public school class, after many years of institutionalization, fires their feelings of guilt at having institutionalized their child. They sometimes panic at being faced with this new decision, after having once made the decision to institutionalize their offspring, in what they believed would be a permanent situation. In this, counseling and therapeutic intervention can be helpful in assisting parents to see their offspring as ever-growing and changing, a person for whom new decisions and choices must be made, the same process as is true for their non-retarded offspring.

Not infrequently, parents are outraged at having to participate in new decisions. The specific alternatives offered to them reawakens the feelings of denial and anger that they felt in the past. Specifically, foster or family care appears to be the most painful choice for parents. While parents frequently argue against half-way houses, hotels and group homes, they are less resistive than to placement of the child in a foster care home. It is psychologically most disturbing to parents.

Parents are frequently heard to say: "Who would want a retarded child and "Only welfare people would take my child, they only want the money, etc." All of these are offered in rejecting the idea of foster care. When the counselor or therapist examines the psychological dynamic involved, it soon becomes clear that the natural family must reject the potential foster care family since the potential foster care parents are most often of the same socioeconomic class, religion and, in many ways, "match" the natural family. Thus, if the natural family has made the decision that they cannot care for their offspring, they reject another person of similar standing.

After having institutionalized their child, often at a very young age, the idea of reincorporating this child into the family seems impossible. For many, institutionalization was a choice that they believed would offer their child better care than they themselves could provide. The idea of a professional offering service on a twenty-four hour basis, whatever the state of the art with regard to

institutional care, gave the family the secure feeling that the child was "in good hands."

In counseling or psychotherapy, these feelings must be addressed, not necessarily by having the parents work through their feelings of having rejected their child. Feelings of guilt are, afterall, incorporations of those prohibitions and moral strictures which are taken from the authority figures in our lives. To make their rejection ego-alien is to reinforce the concept that loving and nurturing are good, whether by the natural parent or the surrogate, and that any resistant feelings which deny these are "bad". The process for this occasion must be one of confronting the parents with the mores by which they live. To reinforce what we consider to be "good" values is not sufficient. We must have the parents learn that certain feelings are ego-alien: to reject what is "bad".